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Improving Engagement and Retention in Adult Care Settings for Lesbian, Gay, Bisexual, Transgender and Questioning (LGBTQ) Youth Living with HIV: Recommendations for Health Care Providers

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Improving Engagement and Retention in Adult Care Settings for Lesbian, Gay, Bisexual, Transgender and Questioning (LGBTQ) Youth Living with HIV: Recommendations for Health Care Providers

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Whether transitioning out of a pediatric/adolescent care setting, or moving directly from the point of diagnosis into adult care, youth living with HIV are entering a system that is not set up to meet their needs. This can have an adverse impact on adherence to medication, treatment for opportunistic infections, and secondary transmission. The situation is further complicated for lesbian, gay, bisexual, transgender and questioning (LGBTQ) youth with HIV who face a multitude of psychosocial and structural barriers due to their sexual orientation or gender identity. Engaging and retaining HIV positive LGBTQ youth in adult care is critical to their survival and to wider prevention efforts, yet many fail to initiate or remain in care. Health and social service providers play a pivotal role in overcoming these challenges. This paper provides a broad overview of the barriers to engaging and retaining HIV positive LGBTQ youth in adult care settings, with particular focus on youth that were infected via behavioral means. Key strategies for overcoming those challenges are then shared. Institutional and environmental solutions include addressing institutional stigma, strengthening the knowledge and capacity of health providers to work with this population, creating a youth friendly environment,

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and solving access issues. Patient-care oriented solutions include improving the patient-provider relationship, offering developmentally sensitive comprehensive services, and directly involving youth in the healthcare setting.

KEYWORDS LGBTQ, youth, HIV, adult care, transition in care, engagement in care

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Every year in the United States, 5,000 youth under age 25 become infected with HIV, mostly due to unprotected sex or needle sharing (CDC, 2012a). In recent years, advances in anti-retroviral medications (ARVs) have significantly reduced AIDS-related mortality, giving these youth the chance to live long and healthy lives. Whether transitioning out of a pediatric or adolescent care setting into adult care, or moving directly from the point of diagnosis into adult care, youth living with HIV/AIDS are entering a system that is not set up to meet their needs. Already, young people ages 15–24 have the lowest utilization of medical office visits than any other age group (U.S. Department of Health and Human Services, 2007). This can have an adverse impact on adherence to medication, treatment for opportunistic infections, and secondary transmission. Engaging and retaining HIV positive youth in adult care is critical to their survival and to wider prevention efforts, yet many fail to initiate or remain in care.

The specific and often unaddressed needs of HIV positive lesbian, gay, bisexual, transgender and questioning (LGBTQ) youth further complicate this issue. This population faces a multitude of psychosocial and structural barriers due to their sexual orientation or gender identity, including mental health problems, homelessness, substance use, and stigma (Mustanski, Garofalo, & Emerson, 2010; Cochran, Stewart, Ginzler, & Cauce, 2002; Corliss et al., 2010). Those that were infected with HIV during their adolescence or young adulthood face the added pressure of coping with a new diagnosis and an unfamiliar health care system, often without the support system that many of their perinatally infected peers grow up with (Valenzuela et al., 2009). The constellation of these factors leaves them at increased risk for discrimination and loss to follow-up.

Few studies have explored how to effectively retain LGBTQ youth (13–24 years old), who were infected with HIV via behavioral means, in adult care settings. The majority of related research has focused on *transition out* of pediatric care settings for perinatally infected youth, and recommendations have mostly targeted pediatric providers (Valenzuela et al., 2009). As the population of transitioning and newly diagnosed LGBTQ youth grows, pushing more young patients into adult care, there is an urgent need to bring this topic to the fore among adult care providers. The goal of this paper is to spur critical thinking and dialogue about a population that is chronically

under-researched and misunderstood. It highlights the unique issues affecting HIV positive LGBTQ youth and identifies key practices that will assist adult health providers as they *welcome and keep youth in* long-term care.

HIV/AIDS AND LGBTQ YOUTH

LGBTQ youth are at increased risk for HIV infection in the United States. At the end of 2009, there were more than 45,000 youth, 13–24 years old, living with an HIV or AIDS diagnosis in the country. In 2010, 76% of infections among males were attributed to male-to-male sexual contact and approximately 15% to perinatal transmission. Among females, 58% of infections were attributed to heterosexual contact and an estimated 35% to perinatal transmission (CDC, 2012a). Male-to-female transgender youth also have particularly high incidence of HIV infection. (Dowshen & D'Angelo, 2011).

The same developmental challenges confront LGBTQ youth as other young people but with the potential added stress of minority sexual orientation and/or gender identity, internal and external homophobia, and limited family and peer support (Garafolo & Bush, 2008). Institutionalized homophobia within schools, workplaces, and health care settings results in high levels of violence toward LGBTQ youth plus disproportionate rates of substance use, mental health problems, suicidal ideation, school drop-out, and sexual risk-taking (Advocates for Youth, 2010). About 20–40% of homeless youth are LGBTQ, often as a direct result of family conflict regarding their sexual orientation or gender identity (Ray, 2006). Internalized stigma, in addition to living with HIV/AIDS, a condition that is highly stereotyped and misunderstood, only exacerbates these problems. The pervasive discrimination and rejection experienced by so many LGBTQ youth on the basis of their sexual identity and/or HIV status means that in terms of health care and day-to-day life, many live in isolation. Therefore, the ability to identify and retain them in care is ever more difficult. Below are certain subgroups of youth who fall under the broad category of LGBTQ. It is important to keep in mind that subgroups are not necessary mutually exclusive; youth may fall across many sub-populations or none at all.

Young Men Who Have Sex with Men

Young men who have sex with men (YMSM), ages 13–24, are the fastest growing population of people living with HIV in the United States (CDC, 2012b), and a high percentage do not know they are infected. Alcohol, methamphetamine, and other drug use are common among YMSM and can lead to risky sexual behavior (CDC, 2012c). For young men growing up in an age where anti-retroviral medications have been readily available, some do

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not view HIV as dangerous and become complacent about the risks (CDC, 2012c). This concern is heightened with recent advances in pre-exposure prophylaxis (PrEP), emtricitabine, and tenofovir (FTC/TDF or Truvada), a promising daily pill to prevent HIV transmission in MSM (Grant et al., 2010). Despite some evidence to the contrary (The Fenway Institute, 2011), advocates fear that the availability of FTC/TDF could lead to a false sense of protection from HIV and increase risk-taking among YMSM (Brooks et al., 2012).

YMSM of Color

Every year, black youth represent half of all new HIV infections in young people ages 13–29 (CDC, 2010), three-quarters of whom are among YMSM. In 2010, 60% of HIV infection in 13–24-year-old men were black/African American, and 20% were Hispanic/Latino, with rising rates every year (CDC, 2012a). Many black and Latino youth are diagnosed late in the course of their infection, putting them at increased risk for opportunistic infections and rapid progression to AIDS (Melendez et al., 2006). LGBTQ youth of color face special challenges. Not only do they experience stigma and discrimination from society at large because of their sexual orientation, but they may also face rejection by their own racial/ethnic communities, many of which strongly oppose homosexuality. Feeling that they have to choose between their ethnicity and their sexual identities, these youth are less likely to be involved with support organizations and activities targeting LGBTQ youth (Advocates for Youth, 2010).

Young Women Who Have Sex with Women

Young women who have sex with women (YWSW) are often thought of as "safe" from negative health outcomes, including HIV infection (Wapenyi, 2010). However, evidence suggests that YWSW also have sex with men. Over their lifetimes, they have similar rates of sexually transmitted diseases to all women, experience pregnancy at higher rates than heterosexual women and are less likely to use protection during heterosexual intercourse (McNair, 2005). Therefore, YWSW have the same sexual and reproductive health (SRH) needs as women who have sex with men, making adequate SRH services crucial for this population. Studies of pediatric HIV care have found that SRH services are limited in the pediatric setting (Dowshen & D'Angelo, 2011). Often, providers assume that HIV positive young women do not want to have children or are not having sex. For sexually active young women, the adult care environment may be much healthier and more helpful in providing access to family planning and counseling services (Vijayan, Benin, Wagner, Romano, & Andiman, 2009).

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Transgender Youth

Male-to-female transgender youth have particularly high rates of HIV infection and many providers are not prepared to manage the complexities of their situations. Transgender youth may be taking or interested in taking gender-affirming hormone therapies or other medications in addition to their anti-retroviral therapy (Dowshen & D'Angelo, 2011). They also experience high rates of violence, victimization, and suicide ideation (McNair, 2005). In 2006, the National Institute of Mental Health reported that transgender women were less likely to receive ARVs than all other people living with HIV (Melendez et al., 2006). It is less likely that a pediatrician will have any specialization in this area, so finding an adult care provider that is knowledgeable and experienced working with transgender youth is likely easier and advisable.

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ENTRY INTO CARE

Some youth will be transitioning out of pediatric health settings, while others will go straight into adult care after diagnosis.

Pediatric/Adolescent Care

Young people that contracted HIV at birth or early in adolescence are likely to have received care in pediatric and/or adolescent health facilities for many, if not all, of their years. Clinically speaking, perinatally infected youth are healthier than they were a decade ago, but a lifetime of HIV means they are more likely to have a history of opportunistic infections, co-morbidities, virological resistance, and learning disabilities (Koenig, Nesheim, & Abromowitz, 2011). In pediatric/adolescent care, medical and psychosocial needs are often addressed together, through a multidisciplinary, "one-stop shop" model. Coordinated services such as these are less likely to be available in adult care settings.

Youth's strong attachment to their adolescent care team, particularly among those who have not disclosed their HIV diagnosis to anyone outside their providers, makes leaving that team particularly challenging. Mutual feelings of attachment, coupled with distrust of the adult care system, mean many pediatric/adolescent providers are equally resistant to let go of their patients (Peter, Forke, Ginsberg, & Schwarz, 2009; Wiener, Kohrt, Battles, & Pao, 2009; Gipson & Garcia, 2009).

Point of Diagnosis

Depending on age, age at diagnosis, readiness and/or clinical protocol, many youth will go directly to adult care without ever entering pediatric or

adolescent HIV care settings. Some newly diagnosed youth enter a period of denial after receiving a positive test result meaning they do not always enter care right away. Equally, a recent diagnosis may mean that youth are still learning to cope, considering suicide and unable to take responsibility for their care (Thom, 2009). They may experience more challenges to treatment adherence, have denial and fear of HIV, and have misinformation about HIV. They will likely have more distrust of the medical establishment, fear, disbelief in the effectiveness of treatment, low self-esteem, depression and anxiety, and an unstructured and chaotic lifestyle without family and social supports (Gipson & Garcia, 2009).

These youth may be experiencing illness for the first time in their lives, necessitating increased assistance with how to navigate the health care system, treatment adherence, and health insurance benefits. If new to the health system overall, young people may bring previously unaddressed issues of substance use, anxiety and depression, intimate partner violence and others that require immediate attention.

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KEY STRATEGIES FOR ENGAGEMENT IN CARE

The following section identifies suggestions for improving and increasing engagement in care for HIV-positive LGBTQ youth. Suggestions were identified through a review of relevant literature as well as current training materials developed for providers who care for LGBTQ youth. The overarching goals for treating this population are to promote healthy development, physical health, and social and emotional well-being by increasing self-care, reducing transmission and high-risk behaviors, and enhancing quality of life (Lighthoot, Rotheram-Borus, & Tevendale, 2007; Garafolo & Bush, 2008).

In general, strategies designed to address these goals fall into two broad categories: Institutional/environmental solutions and patient care solutions.

Institutional and Environmental Solutions

The way in which a patient interacts with his/her environment upon entering the clinical setting can have a major impact on whether or not he/she remains engaged in care. As suggested by this anecdotal evidence from an HIV positive young adult that started his care in an adolescent health care setting, an adult care environment that seems sterile and filled with people that youth cannot identify with (e.g., older, sickly) could keep a young person from returning for care:

> One of the most important things that an adult provider needs to recognize is that first impressions are everything. If youth don't feel welcome

> or they are made to feel inferior or not intelligent—especially if they are not cognitively ready to navigate the situation—chances are they are not coming back and they will be lost to care. (personal communication, Male, 29, Ohio, March 2012)

Strategies designed to improve retention in care at the institutional level consider the makeup of the physical environment, appropriate messaging for HIV positive LGBTQ youth, provider education, and solving access issues.

Address Institutional Barriers

The Institute of Medicine's (2011) report on the health of LGBTQ people identifies significant health disparities for youth and adults. Their findings suggest that individuals as well as institutions play a role in perpetuating these disparities. LGBTQ patients often face difficulties in accessing quality health services due to stigma, both real and perceived, within the medical community. Recognizing short-falls at the institutional level, such as a workforce unaccustomed to treating LGBTQ patients and the lack of LGBTQ-specific clinical protocols, is a first step in creating a health system that is appropriate and accessible for LGBTQ youth with HIV.

Provider Education

Lack of education and training for health professionals surrounding the specific needs of LGBTQ youth and communication shortfalls during clinical visits (Garafolo & Bush, 2008) can have an adverse impact on a patient's health-seeking behavior and adherence to health recommendations. Previous research indicates that many primary care physicians are uncomfortable with homosexuality and LGBTQ individuals are hesitant to share their sexual orientation with their providers (Klitzman & Greenberg, 2002). Many providers receive little training on the health care needs of LGBTQ individuals, and medical schools rarely offer specific information on LGBTQ health risks (Makadon, 2006). Institution-wide training of health care professionals on culturally sensitive means of communication with LGBTQ youth as well as their health needs can help decrease the effects of structural stigma.

HIV positive LGBTQ youth often experience high levels of distrust of the health care system (Gipson & Garcia, 2009). Young people return to environments where they know people care for them (U.S. Dept. of Health and Human Services, 2007). Empathetic and nonjudgmental providers can encourage a young person to enter and remain in care. Further, most HIV positive and LGBTQ youth have experienced trauma in their lives. However, many have also demonstrated significant resiliency in the face of adversity (Levine, 2009). The use of a strengths-based model rather than a

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deficit-based model will likely improve retention in care (U.S. Dept. of Health and Human Services).

Create a Welcoming Physical Environment

Pediatric and adolescent health settings are often decorated with culturally and age-appropriate artwork, equipped with relevant resources and brochures, and staffed by people that are enthusiastic about working with youth.

> In our adolescent clinic, the walls are covered in graffiti and there are resources and flyers for youth. It's open on Saturdays. The adult clinic is not youth-friendly. The problem is that if they [youth] don't like it, they won't go. (personal communication, Male, 20, Boston, February 2012)

See Table 1 for specific suggestions on creating a youth and LGBTQ friendly environment.

Solve Access Issues

Health care access is a major issue for HIV positive LGBTQ youth due to lack of insurance, homelessness and unemployment. In rural settings, patients must travel a substantial distance for HIV, mental health, and substance use care. Many young people fear disclosure by insurance companies to parents or guardians so they access care in community-based settings that do not require health insurance (Garafolo & Bush, 2008). HIV positive LGBTQ youth may not know where to go for LGBTQ and youth friendly care, and negative experiences could persuade them to disengage completely. Alternatively, facilitating care can make a significant difference in patient outcomes. For example, a recent study by the Health Research and Services Administration (HRSA) found that newly diagnosed, HIV positive young black MSM are more likely to go to their first doctor's appointment if the person who diagnoses them picks up the phone and schedules that appointment (Hightow-Weidman et al., 2011).

Patient Care Interventions

Access to high quality patient care plays a pivotal role in addressing the physical and mental health needs of LGBTQ youth. Important aspects of quality care include the patient-provider relationship, offering developmentally sensitive comprehensive services, and directly involving youth in the healthcare setting.

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TABLE 1 The Physical Environment

Creating a Youth-friendly Environment*	Creating a LGBTQ-friendly Environment**
Hold **flexible clinic hours** on weekends and in the evenings. Make sure someone is there to greet young people when they walk into the clinic so they feel **welcome.**	Provide comprehensive **training** for all clinic staff in the care and rights of LGBTQ youth. Make sure to include "frontline" staff; those that youth will interact with when they first walk in the door.
Cluster medical and mental health appointments together, and schedule them alongside other peer support and case management activities so youth have more of a **"1-stop shop".**	Post a visible **non-discrimination statement** stating that equal care will be provided to all patients, regardless of age, race, ethnicity, physical ability or attributes, religion, sexual identity and gender identity.
Provide **travel** vouchers for public transportation.	Have **posters and flyers** with racially diverse, same-sex couples and transgender youth.
If possible, create a **separate waiting area** for youth in which they can congregate, check email, etc. Provide **childcare** for youth with small children.	Provide information about safe sex, HIV prevention, and/or pregnancy prevention that is **appropriate** for LGBTQ youth (e.g., resources that only talk about heterosexual couples may not be received well).
Integrate intensive **case management** and relevant psychosocial support services.	Provide appropriate resources and referrals for **LGBTQ-friendly services** such as mental health, substance use and peer support.
Actively **involve** young people in program design and delivery.	**Involve** LGBTQ youth in the planning, delivery and evaluation of your program.
Expand **social media** use for engagement and retention (e.g., mobile phones and Facebook for appointment and medication reminders, and accessing results. Give youth beepers when they arrive for care so that they can leave the waiting room and be called back when they are ready to be seen.)	Discuss racism, sexism, homophobia, and other forms of cultural oppression in your program. Get young people to generate ways to solve, limit, or minimize the problems caused by cultural oppression.
Provide information and materials that are appropriate for young people.	**Refer** patients to providers that are enthusiastic about working with LGBTQ youth.

*Adapted from Young Adult Program, St. Lukes Roosevelt Hospital, New York City.
**Adapted from Advocates for Youth, Creating Safe Space for GLBTQ Youth: A Toolkit (2005)

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Patient-Provider Relationship

Previous research indicates that poor patient-provider communication is associated with adverse health outcomes and decreased adherence to medical advice (Cortes et al., 2009; Stewart, 1995). Therefore, it is important for providers to be aware of how and what they are communicating to LGBTQ youth. A survey of LGBTQ youth found that they desire the same clinician characteristics of privacy, honesty, respect, and a nonjudgmental

perspective as do other adolescents (Ginsburg et al., 2002). However, findings also indicated that providers must learn how to gather important health-related information in a sensitive manner so as not to further alienate youth from care. Avoiding assumptions about patients' sexual identity and behavior is paramount. Levine (2009) suggests normalizing sexuality during provider patient conversations and offers several suggestions for avoiding heterosexist questions. For example, the question "Do you have a girlfriend?" directed at a YMSM patient may shut down further communication about sexual behavior. An alternative question is "Are you seeing anyone?". Table 2 offers additional suggestions on how to avoid assumptions and bias.

Building a positive and trusting relationship with patients is the cornerstone of engagement and retention in care. For vulnerable youth, this means being proactive, sensitive, and compassionate. Spend extra time with new patients, helping them understand the significance of learning and understanding their lab results, adherence and building relationships with providers. Assist them with their autonomy and self-acceptance, concerning both their sexual orientation/gender identity and their HIV status. Create open and honest dialogue, particularly around sensitive issues. Remind them that what they say is confidential and that they can trust you. Be prepared to make appropriate referrals and recommendations, particularly for case management, mental health, housing, substance use and peer support.

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TABLE 2 Patient-Provider Relationship

Asking the Right Questions Can Make a Difference
Young people may identify their sexuality differently from the way they behave.
• *Ask whether the patient has had sex with men or women or both, regardless of how he/she identifies.*
Your patients are people. Get to know them and their interests to strengthen their relationship.
• *Ask open-ended questions like "What do you do for fun?" to help them feel normal.*
Sexual behavior and identity can change over time.
• *Ask about previous sexual behavior or sexual desires at every visit.*
Being in a committed relationship does not always equal monogamy.
• *Ask questions about concurrent sexual partners.*
Youth may only identify sex as penile-vaginal intercourse.
• *Ask about whether he/she has had vaginal, anal or oral sex in the past.*
Gender identity is distinct from sexual orientation.
• *Don't assume transgender implies gay.*
Your patient is also an expert.
• *If you need help with all of these terms, ask the patient to help define them!*

Adapted from Fenway Guide to LGBT Health Module 2 and the Gay and Lesbian Medical Association (GLMA).

Developmentally Sensitive Comprehensive Services

> Often providers expect youth to be fully able to engage in care the same way an adult will; that is not the reality. Especially if they have never dealt with care settings or have always had it dealt with for them. There are small steps that any setting can take to engage youth in a way that it is going to be affirming, accepting and meeting them where they are. (personal communication, Male, 29, Ohio, March 2012)

HIV positive LGBTQ youth need developmentally and culturally appropriate services that provide support and care for a range of medical and psychosocial issues. There is no prescribed age for transition to adult health care, though the majority of clinicians in the United States try to transition HIV positive youth into adult care by the age of 24 (Vijayan et al., 2009). That being said, chronological age is different from developmental age. Patient readiness and maturity are crucial to determining healthy engagement in care (Fair, Sullivan, & Gatto, 2010).

Assessing the patient from an ecological perspective, taking note of all of the biopsychosocial determinants that influence his/her health, in addition to making appropriate referrals for psychosocial services, is essential. Where possible, involve a social worker and/or case manager who can assess and address pressing issues. If a young person is transitioning from a pediatric/adolescent care setting, communication between provider teams is important (Wiener et al., 2009). It is also important to provide case management services to support youth with transportation, health insurance, and benefits. Linking youth to peer support groups can help keep them engaged in their care, as well as having a list of providers within each region ready at each point of diagnosis to ensure seamless referral into adult care settings. Table 3 highlights some of the key psychosocial support needs of this population.

Included in the provision of developmentally sensitive comprehensive care is an intentional integration of sexual and reproductive health (SRH) services. Comprehensive, LGBTQ, and youth-friendly SRH services are essential for this population. Young people may practice unsafe sex as a coping mechanism to deal with a recent diagnosis or stigma, or as a means of gaining peer acceptance (Clum et al., 2009; Elkington et al., 2009; Wiener, Battles, & Wood, 2007). Sexual curiosity and risk-taking are inevitable components of adolescent development. Like their uninfected peers, LGBTQ youth living with HIV have the right to seek sexual fulfillment and they should be equipped with the knowledge and skills to protect themselves and their partners. Table 4 identifies suggestions for integrating SRH services into regular care.

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TABLE 3 Addressing Important Psychosocial Support Needs

Adherence: Recognize that adherence is especially hard for young people living with HIV, particularly if they are struggling with many other aspects of their lives. Ensure that adherence support, through peer and professional counseling, is provided for all young people taking medications.
Substance use: Some youth need harm reduction education, motivational interviewing and/or introduction to rehabilitation and recovery therapy.
Longer-term housing: Transitional living programs for homeless youth offer an active alternative to shelters and can be designed to meet the specific needs of this sub-population.
Mental health: Understand that depression, anxiety and suicide ideation are both predictors and consequences of an HIV diagnosis. Screen for these issues and refer appropriately.
Disclosure: Recognize that disclosure of HIV status to others is one of the biggest concerns for HIV positive youth. Provide information and counseling surrounding healthy and safe disclosure to others.
Partner violence: Many LGBTQ youth living with HIV face high rates of intimate partner violence, particularly after disclosing HIV status. Programs should incorporate counseling, support and education surrounding domestic violence.
Peer support: Peer support can be offered through regular support groups, one-to-one mentorship, youth conferences, and social activities where education is provided in a fun setting. The role of older peers who have successfully transitioned and are engaged in adult care, who can serve as mentors, cannot be overstated.
Structural support: Link youth to services and programs that focus on money management, credit, decision-making skills, job training and educational opportunities.

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Directly Involve Youth

The meaningful involvement of youth living with HIV in the planning and delivery of their care and support is a critical and often underaddressed component of youth engagement in adult care settings (Greifinger & Dick, 2011). Putting youth at the center of their care will not only ensure that their individual needs are met but also that the system as a whole becomes more effective at service provision and patient retention. Create a mechanism for

TABLE 4 Providing Sexual and Reproductive Health Services

Support young people with information and education surrounding positive sexual health and prevention, self-esteem, self-efficacy and the ability to manage high-risk situations.
Provide social support services and counseling surrounding **family planning** and parenthood.
Link pregnant youth to appropriate **antenatal care** and education and counseling on how to reduce the risk of mother-to-child transmission during pregnancy, delivery and breastfeeding.
Ask youth about their **fertility intentions** and desires. Recognize that expectations for sex, intimacy, loving relationships, children and family are no less evident in HIV positive young people or in those that are LGBTQ.
Provide appropriate support for youth involved in **survival sex work** (providing sex for money or resources), particularly if they are homeless.
Provide **assertiveness training**, particularly for those youth still struggling with "coming out." This should include training on condom negotiation and communicating about safe sex options.

young people to offer feedback to providers about the quality of care they are receiving. This can be done through anonymous suggestion boxes, youth advisory boards, peer education trainings, and other outreach opportunities where young people speak out to clinicians and the wider public. Create safe spaces for young people to meet and network with one another within the clinic setting. Knowing they are not alone will strengthen their voice and their incentive to stay engaged in care. Teach decision-making skills so youth are able to make informed decisions around high-risk behaviors as well as important decisions about their healthcare. Where possible, provide paid or volunteer opportunities for young people to work in the clinic, particularly as peer educators and counselors.

STRENGTHS AND LIMITATIONS

This paper identified several strategies that may help improve medical systems and provide health professionals with suggestions to improve the quality of care provided to LGBTQ youth living with HIV. However, there are few studies that actually assess the effectiveness of specific models of care for this population. Future research must focus on developing guidelines based on qualitative and quantitative evidence and should examine: 1) the influence of training health care providers on the use of gender neutral language when taking a sexual history on patient satisfaction, quality of information obtained, and provider comfort levels; 2) the effects of offering comprehensive mental health services within the context of infectious disease care; 3) the role that the physical environment has on appointment attendance, accessing wrap-around services, patient satisfaction, etc.; and 4) interventions addressing linkage to care for LGBTQ youth testing positive for HIV in non-primary care settings.

CONCLUSION

LGBTQ youth living with HIV in the United States remain a hidden population. Stigma and misunderstanding at the individual, community and institutional levels, coupled with a health workforce that is not trained to receive them, pave the way for a disease burden that is impossible to manage. Failing to successfully engage and retain these youth in adult care not only jeopardizes their health and wellbeing; it threatens the success of HIV prevention efforts to date, which could cost valuable lives and resources. Medical providers are in a unique position to help this at-risk population of youth enter and remain in care. It is timely and urgent that we begin an honest and proactive dialogue about equipping providers with the training, resources, and support they need to provide optimal care for HIV positive LGBTQ youth.

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